

Public engagement with cohort participants in Scotland and India: How do participants want to shape mental health research?

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Introduction

We now have the opportunity to disentangle the complexities of lifespan brain health through linking rich birth cohorts data to novel information utilizing health informatics techniques. Wellcome Trust evidenced that efforts to manage and link digital health data require exploring the attitudes of public and data guardians towards this initiative.

Objectives and Approach

Our teams in Aberdeen, Mysore and Mumbai have established general population cohorts that have provided evidence on the early-life origins of later-life diseases. In 2016, we engaged with the participants of the Aberdeen Children of the 1950s (62-68, N~8,400) in an event attended by 350 study members. We are also engaging with members and data guardians of Mysore Parthenon Cohort (20-21y, N~500), Mysore Birth Records Cohort (51-83y, N~750), and Mumbai Maternal Nutrition Cohort (5-11y, N~1,600). This qualitative project utilises focus groups and individual interviews. The goal is to understand their attitudes and perceived public benefits towards future novel data collection, data platforms and biorepositories.

Results

The ACONF event attendees were very willing to volunteer for further studies. The highest support was for 'provide a blood sample' (92%) and the lowest for 'take an online survey' (83%). They were satisfied with data governance but had incomplete understanding of linkage possibilities with their data. Through the ongoing activities in Mysore and in Mumbai, we aim to achieve the following: 1) Develop awareness of health informatics through public engagement with participants and researchers; 2) Explore attitudes and potential barriers to creation of secure data linkage between imaging, laboratory, health data and outcomes to facilitate future linkage studies; 3) Understand what is required for interoperable, secure data storage and plan future biorepository as a resource for researchers that will build over time in India.

Conclusion/Implications

The proposed activities will inform preparation of a large scale grant to investigate the hypothesis that early life environment affects future risk of mental illness and cognitive ability globally. They will also begin to create a platform of enduring value for future cross-cultural population research.

